Available online at www.sciencedirect.com
SCIENCE DIRECT®
Health Policy 74 (2005) 157–166
HEALTH policy
www.elsevier.com/locate/healthpol

When being 'tired of living' plays an important role in a request for euthanasia or physician-assisted suicide: patient characteristics and the physician's decision

Mette L. Rurup*, Bregje D. Onwuteaka-Philipsen, Marijke C. Jansen-van der Weide, Gerrit van der Wal

VU University Medical Center, Department of Public and Occupational Health and Institute for Research in Extramural Medicine, van der Boechorst straat 7, 1081 BT Amsterdam, The Netherlands

Abstract

Background: In the Netherlands physicians are allowed to grant requests for euthanasia or physician-assisted suicide (EAS) if they meet several requirements of due care. According to jurisprudence, a physician is not allowed to end the life of a patient whose request for EAS is based on being 'tired of living', because such a request falls outside the medical domain. Our previous studies have shown that in spite of this, such requests are made approximately 400 times a year.
Objectives: To learn more about patients who request EAS because they are tired of living, and about factors that influence the decision of the physician.
Design: Questionnaires ($n = 4842$) completed by general practitioners ($n = 3994$).
Results: According to the physicians, 17% of patients who requested EAS were 'tired of living'. Of 139 patients in whose request for EAS being tired of living played a major role, 47% suffered from cancer, 25% suffered from another severe disease and 28% had no severe disease. In all three groups the same three symptoms occurred most frequently, 'feeling bad', 'tired', and 'not active'. Each of these symptoms occurred in more than half of the patients in each group. Most of the requests from patients with cancer were granted, but those from patients who had some other severe disease, or no severe disease at all, were refused. Factors that were related to granting a request were: the presence of unbearable and hopeless suffering, the absence of alternatives, and the absence of depressive symptoms.
Conclusions: Being tired of living can play a major role in requests for EAS, both in the absence and the presence of a severe disease. The high occurrence of symptoms in the absence of a classifiable severe disease implies that physical symptoms are prevalent in this group of patients, leaving the legal requirement for EAS of 'a medical cause' open to interpretation in the more complex medical practice.

Keywords: 'Tired of living'; Physician-assisted suicide; Request; Euthanasia; Ageing; Medicalisation

* Corresponding author. Tel.: +31 20 4449690; fax: +31 20 4448387.
E-mail address: m.rurup@vumc.nl (M.L. Rurup).

0168-8510/$ – see front matter © 2005 Elsevier Ireland Ltd. All rights reserved.
doi:10.1016/j.healthpol.2005.01.002

1. Introduction

In the Netherlands physicians are allowed to grant requests for euthanasia or physician-assisted suicide (EAS) if they meet the requirements of due care, which include the patient's request being voluntary and well-considered, the patient's suffering being unbearable and hopeless, and the absence of treatment alternatives. Jurisprudence from 1994 states that the extent of the suffering is determined by the way in which it is experienced, and should be abstracted from the cause. However, jurisprudence from 2002 adds to this that the cause must be medical: if a patient is suffering from the consequences of old age and requests EAS because (s)he is 'tired of living', but does not suffer from a severe disease, the physician is not allowed to grant such a request [1]. One of the reasons for this, as given by the Supreme Court, is that a physician is a medical expert, and can therefore judge the extent of unbearable and hopeless suffering of a patient with a medically defined disease, but is not an expert in dealing with patients who are tired of living, and therefore cannot judge their suffering or the adequacy of their treatment. Moreover, the law regarding EAS was intended to be applied to patients with a severe physical or psychiatric disease, and not to patients who have ailments due to old age and are tired of living.

Apparently the diagnosis of a particular severe disease and a physician's knowledge of the accompanying clinical picture is considered to be very important in assessing (the extent of) the suffering. However, such an assumption seems to ignore the subjective aspect of the patient's experience of the extent of the suffering. It is known that in most cases the most important reasons for patients to request EAS are not physical symptoms, such as pain, but psychological reasons, such as loss of dignity, deterioration and loss of meaning [2,3].

Our previous studies have shown that in the Netherlands explicit requests for EAS from patients who are 'weary of life' occur about 400 times a year [4]. In this article we aim to answer the following questions: To what extent does being tired of living, as a reason for requesting EAS, occur in the presence or absence of a severe disease? What are the characteristics and symptoms of patients who request EAS because they are tired of living? And what are their reasons? Do physicians grant requests from patients who are tired of living and, if so, in what cases?

2. Methods

2.1. Definitions

Euthanasia is defined as the administration of drugs with the explicit intention of ending the patient's life at his/her explicit request. Physician-assisted suicide is defined as the prescription or supply of drugs at the explicit request of the patient with the explicit intention to enable the patient to end his/her own life.

2.2. Measurement instruments and study population

The data used in this article are derived from the evaluation study of the project 'Support and Consultation on Euthanasia in the Netherlands' (SCEN) [5]. SCEN is a network of especially trained physicians from whom general practitioners (GPs) can obtain information and advice, or request a formal consultation (required for the euthanasia notification procedure). For this study all GPs in 18 (out of 23) general practice regions in the Netherlands received a post-test questionnaire approximately 18 months after the start of SCEN in their region (in 2001 and 2002). All GPs in 4 of these regions had also received a pre-test questionnaire shortly before the start of SCEN.

Both for the pre-test and the post-test, the addresses of all GPs working in these regions were obtained from GP registers. Of the 1931 GPs who received a pre-test questionnaire, 177 were no longer working in the region, or had retired, or were ill, and 1227 GPs returned the questionnaire (response 70%). Of the 6596 GPs who received a post-test questionnaire, 556 were no longer working in the region, or had retired, or were ill, and 3615 GPs returned the questionnaire (response 60%).

The part of the pre-test and the post-test questionnaire that is relevant for this article is that in which the GPs were asked to describe their most recent case in which a patient had requested EAS. In the pre-test this applied to requests from January 1998 onwards, and in the post-test this applied to requests that had been made in the past 18 months. In the pre-test such a request was described by 718 GPs, and in the post-test by 1701 GPs. Because the implementation of SCEN is not relevant in this article, the requests described in the pre-test were added to those described in the post-test.